A Sister’s Journey as an Organ Transplant Advocate

The woman’s uninsured brother needed a liver transplant. She fought to get him on a donor list and a transplant.

August 29, 2022 By Laura Schmidt

When Taayoo Murray’s brother was diagnosed with an incurable liver disease, she did all she could to advocate for his life-extending organ transplant.

In 2016, Murray’s brother was diagnosed with primary sclerosing cholangitis, a liver disease that resulted from ulcerative colitis. The diagnosis is rare and incurable and without a liver transplant leads to liver failure. Murray’s uninsured brother’s health was deteriorating, and care options were limited due to high out-of-pocket costs and long waiting lists.

That’s when Murray started learning about organ transplantation and became his advocate.

Murray told Insider that she researched her brother’s condition so that she could ask doctors the right questions regarding prescription medications, certain procedures and more. Eventually, doctors stopped giving standard “canned responses” and started including Murray in conversations about her brother’s treatment plans.

Murray’s consistent advocacy led to relationships with medical providers and social workers who helped in navigating treatment without health insurance and securing him a spot on the donor list.

In 2018, Murray’s brother received his transplant. He has had no complications related to the transplant and is healthy, back at work and “living his best life.”

While liver transplants are generally successful, only about 9,000 transplants are performed in the United States every year. Having an educated, proactive advocate is important not only to secure a spot on the donor list but also to receive a timely transplant.

Black people have a particularly difficult experience getting organ transplants. In fact, Black people make up about 29% of the waiting list and accounted for only 12.9% of organ donors in 2020. Lack of awareness, distrust of doctors and fear of racism are a few barriers to donation they face.

To learn more about obstacles surrounding liver transplants, read “Left Off Liver Transplant Waiting Lists.”

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